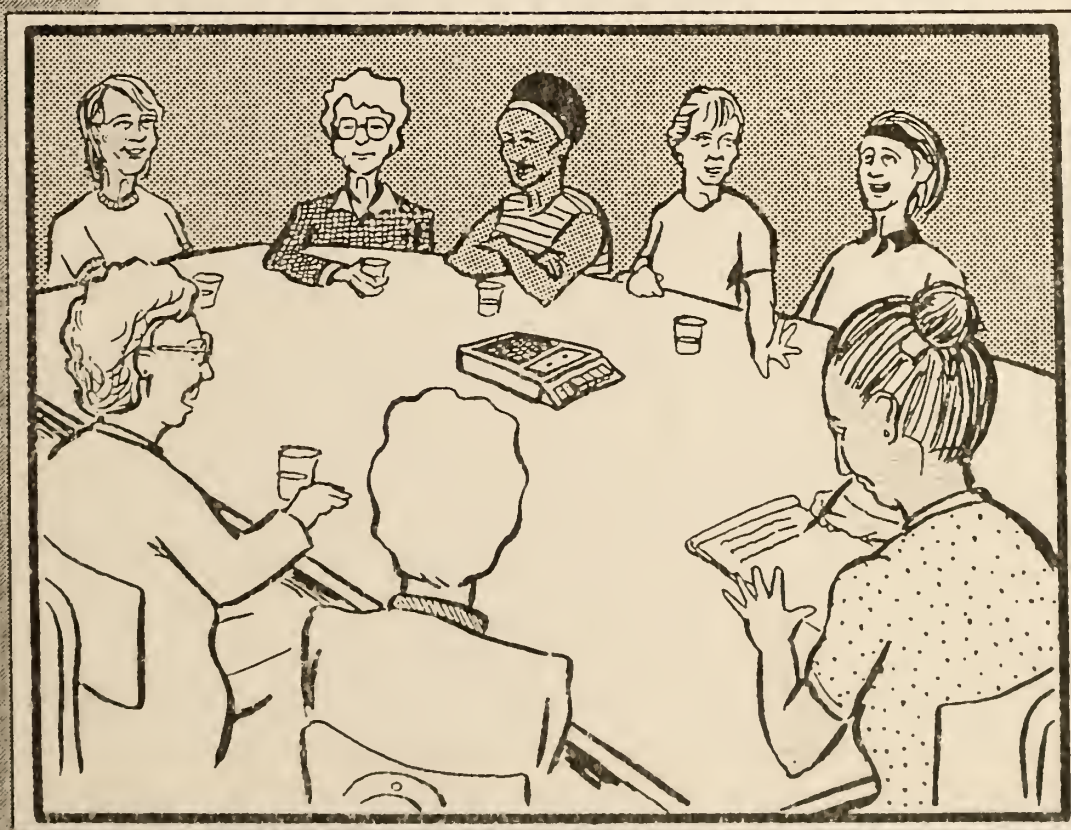


Office of Minority Health
Research Center
PO Box 27337
Washington, DC 20013-7337

Listening to Your Audience:

Using Focus Groups to Plan Breast and Cervical Cancer Public Education Programs



prepared by
AMC Cancer Research Center
1600 Pierce Street
Denver, Colorado 80214

in cooperation with & supported by
Centers for Disease Control and Prevention
Cooperative Agreement #U50/CCU806186-03

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◆ Introduction

Qualitative research can yield a more in-depth analysis than that provided by formal quantitative methods (Mariampolski, 1984 in Krueger, 1988).

As health educators and researchers, we are constantly seeking more effective strategies to reach our audiences with health information and to motivate them to adopt healthier lifestyles. Too often we have relied almost solely on our previous experiences and the knowledge and experiences of others to design our programs. We have found, however, that this is not enough. We must listen to and work with our audiences to develop effective programs which meet *their* needs, not *ours*. Qualitative research offers us some of the mechanisms to do this.

Many techniques, including focus group and individual in-depth interviews, fit under the rubric of "qualitative research." These techniques enable the health educator and researcher to gain insight into the attitudes, beliefs, perceptions and behaviors of their study populations. Qualitative research provides a depth of information about populations that may not be provided through quantitative research. It is also used to provide a framework which can assist in the interpretation of quantitative data. In program planning efforts, we need to utilize both forms of research. One complements the other.

◆ About this Guidebook

This guidebook addresses only one of the techniques of qualitative research: the focus group interview. As you will see after reviewing the guide, there are certain limitations to the use of focus groups. You will also discover the richness of information provided through focus group research about women's attitudes and behaviors regarding breast and cervical cancer screening. The hope is that you will come away with not only a greater understanding of this qualitative research methodology, but also with a heightened sensitivity to the importance of involving your program's intended audience in its development, from conceptualization through to implementation and evaluation.

This guide was developed primarily for staff of state health departments who are developing breast and cervical cancer public education programs with funding from the Centers for Disease Control and Prevention. These staff are being challenged to design programs to reach women not traditionally served by public education efforts in cancer control. These underserved groups include a diverse population of women, such as low income Native American, Hispanic, African American, and Asian American women. In addition, the needs of women who have limited or no reading skills are being addressed in these programs.

In addition to staff of state breast and cervical cancer programs, we hope that this guide is also helpful to others who are interested in using focus groups in designing health education programs and communication efforts.

In August, 1990, Congress signed the Breast and Cervical Cancer Mortality Prevention Act into law. This law appropriated funds for the Centers for Disease Control and Prevention (CDC) to disperse to state health departments for the establishment of comprehensive breast and cervical cancer screening programs. Specified in the law was the provision of services to low income and minority women. States were thereby faced with the challenge of reaching women traditionally underserved by breast and cervical cancer screening services.

♦ About this Guidebook

The guidebook is organized into three sections:

Section 1: Focus Group Methodology

The first section provides basic information regarding focus group methodology and use. Its intent is not to provide "how-to" information for conducting focus groups, but rather to describe key planning issues to be considered.

Section 2: Breast and Cervical Cancer Screening Programs: What Focus Groups Have Found

This section summarizes the results of 133 focus groups on breast and cervical cancer public education programming. The reports of these focus groups were collected nationally from researchers and health educators interested in designing educational and outreach programs to reach underserved women.

Section 3: Qualitative Research Among Very Low Income Populations

The final section of the guide describes issues to consider when conducting qualitative research among very low income populations. Issues addressed include recruitment, types of qualitative research that may be most appropriate for low income communities, and the costs and benefits of utilizing modified focus group techniques.

◆ Section 1: Focus Group Methodology

Why Focus Group Research?

Interest in focus group research has increased tremendously over the past two decades, particularly among health education program planners and researchers. Focus groups provide us with insights into the feelings, attitudes, beliefs and behaviors of our audiences. Compared to other forms of research, focus groups may be relatively inexpensive, and provide a rich source of information essential to the design of effective health education programs. The nature of group dynamics, upon which focus group methodology is based, offers certain strengths as well as limitations to this form of research. Small groups provide a safe setting to explore differences among members of the intended audience. They also provide a forum through which the researcher can learn audience attitudes and perceptions on specific issues in a setting which allows for interactions among audience members, which is how most attitudes and perceptions naturally develop.

Purpose and limitations

Information derived from focus group interviews may be used for several purposes:

- ▶ to generate program concepts
- ▶ to develop instruments for quantitative research
- ▶ to pretest materials
- ▶ to assess audience needs
- ▶ to identify the scope of issues important to the population

Limitations to focus group methodology include:

Results are not generalizable to the larger population.

Sample sizes are relatively small and the study participants have been selected based on specific characteristics that are "typical" of the intended audience, yet not representative of that audience.

Focus groups are not intended to develop consensus, to arrive at an agreeable plan, or to make decisions about which course of action to take (Krueger, 1988).

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Care is needed to avoid lifting comments out of context and out of sequence or to come to premature conclusions (Krueger, 1988).

Researcher has less control than when using individual interviews. Group members are able to influence the course of the discussion, sometimes leading it away from the issue of concern. The moderator must then use his/her skills to gently bring the discussion back. In addition, it can take considerable time for a group to fully discuss an important issue. This may be viewed as somewhat inefficient use of time as there are generally several topics the researcher would like to have covered during the discussion.

Interpretation and analysis of results. Data reduction is difficult. The procedures used in analyzing focus group results are not standardized. In addition, it is difficult to quantify the importance of issues raised by participants or prioritizing needs. For example, if three out of ten participants mention cost as a barrier to obtaining a mammogram, this can not be interpreted as being a barrier for 30% of the population. Further, comments made by participants must be interpreted within the context of a "social environment" (Krueger, 1988). All too often, researchers will be tempted to take a comment made by a single participant in one of the focus groups and design a program around it. Conducting more than one focus group and comparing responses often allows for a more valid and precise understanding of salient issues. Researchers and program planners must take the discussion dynamics into consideration, as well the comments made by all the participants when analyzing focus group results. Researchers must be cognizant of the environment in which the discussion occurs and comments are made. As an example, one very vocal member of the group may lead others to agree that a particular problem is of great importance, when prior to participation in the group, members did not perceive it to be.

As you will see in the section "*Selecting a Moderator*", the skill and characteristics of the moderator facilitating the discussion are extremely important in eliciting comments from all the participants specifically on the topics of concern to the study.

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The methodology

The following table presents some characteristics of focus groups which are important to consider when planning your groups.

Focus Group Characteristics	
Description	Reason
Group Composition 6-12 participants	• small enough so that all should have opportunity to share • large enough for diversity of views • groups larger than 12 have a tendency to fragment
Location for Group neutral easy to find	• groups held at a location affiliated with the sponsoring organization may influence the participant's responses • reduces transportation problems
Room Set-up chairs placed around a table participants facing each other	• enable participants to be less conscious about their bodies • enables participants to have eye contact
Number of Groups 2 or more per topic	• provides input from enough groups to balance any idiosyncracies of individual groups
Eligibility Criteria Race, ethnicity, age, income, gender, health behaviors	• depending upon what you are studying, certain participant characteristics may or may not be important
Recording/Observation audiotape videotape one-way mirror observer/recorder to assist moderator	• enhances ability to recall specific comments made by participants, able to include direct quotes in report • enables nonverbal responses to be recorded and included in report • enables researchers and other interested parties to view the group interaction without interfering • enables moderator to refrain from taking notes, records nonverbal responses without requiring use of videotape which may inhibit discussion

(adapted from Krueger, 1988)

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Recruitment

Eligibility criteria

Once you have decided upon the characteristics of the individuals you want to participate in the focus groups, you can develop the eligibility criteria. Some examples of eligibility criteria include age, race, ethnicity, income, and gender. Other criteria may be added based on how narrowly defined your intended audience is. For example, if your program is for women who have never had a mammogram, you may decide to include mammography utilization as one of your criteria. Criteria should be agreed upon by all members of your team (researchers, program planners, community members) and understood by the recruiters before the process begins.

You should have very specific eligibility criteria before you start recruitment. Developing the screener's questionnaire will help you to focus on who should be in the group and where to locate your potential participants. The screener's questionnaire in Appendix A is an example of the types of questions recruiters should ask.

When screening potential participants, care must be taken not to disclose too much detail about the purpose of the groups. Prior knowledge about the specific topics to be discussed could lead to biased responses. In addition, some of the questions you ask in your questionnaire can lead participants to think that the discussion is to be focused on a certain issue, which they may then come prepared to talk about. However, it is important to honestly respond to questions of the participants regarding why they are being asked to participate. Broad responses can be used without revealing the specific intent of the group. For example, a group on breast cancer can be described as a discussion on women's health issues.

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A Case Example

Researchers using questions regarding insurance status and "utilization of public health clinics" as proxies for income in their screener's questionnaire found that the questionnaire itself can influence the discussion. In the first few groups conducted with women who were recruited using this questionnaire, the women came to the groups ready to voice their concerns about the cost and inadequacies of health insurance. The questions had given the women the impression that the focus of the discussion was to be health insurance and the costs of health care. It was difficult for the moderator to pull the women back to focus on the questions of concern to the researchers. In subsequent groups with women recruited by this means, the moderator acknowledged the women's concerns with insurance at the onset of group, and informed the women that the focus of the discussion was not to be on this issue. She was then able to continue with the questions in the discussion guide.

Recruitment Strategies

Several strategies exist which can be used to recruit focus group participants. The following table lists some of these strategies.

Focus Group Recruitment Strategies	
Telephone	• names and numbers obtained from market research database • names and numbers obtained from community organization lists
Poster	• located in various community sites • encourage persons to call for more information
Face-to-face	• locations to recruit from: supermarkets, movie lines, clinics, churches, shopping malls
Via Gatekeepers	• key contacts in the community, e.g., pastors, directors of community organizations • make the initial contact for recruiter

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For most population groups, the most efficient way to recruit is through the assistance of a "gatekeeper." The gatekeeper is someone known to members of the community from which you are seeking to recruit participants. This strategy has its benefits, especially when you are seeking to involve members of very low income communities. Using a gatekeeper may also be the most labor intensive recruitment strategy, both on the part of the gatekeeper and research staff. Recruitment of low income populations will be discussed in greater detail in Section 3 of this guide.

The least labor intensive way to recruit individuals for focus groups is by telephone. Market research firms generally have computerized databases from which they can draw names of potential participants. These databases usually contain names of persons that the firm has contacted in the past and who expressed interest in participating in a focus group, as well as people these individuals referred to the firm. The database contains information related to the person's place of residence, gender, age, race, ethnicity, and consumer behavior. Market researchers use the database to contact persons by phone to enlist their participation.

Frequently, individuals whose names are contained in these market research databases are not of very low income. For program planners and researchers who are interested in conducting focus groups with low income participants, this method of recruitment is not suggested.

In addition to questions related to the eligibility criteria, it is also important to ask the potential participants if they need assistance with transportation or child care in order for them to participate. It is also helpful to have the name and telephone number of the project director for the respondents to call if they are questioning the legitimacy of the study. If you are working through a community organization or church to recruit the participants, it is helpful to have the name and telephone number of the director or pastor for potential participants to call for assurance. It's always better to have available the name of someone for individuals to contact who is known to them and trusted in the community.

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Always offer refreshments and a snack. If the timing of the group interferes with lunch or dinner time, offer a meal. Food shows your appreciation for the participants' involvement and sets a more relaxed atmosphere or mood. Serve foods that are appropriate for your participants' culture and diet.

Helpful Hints for Recruiting Focus Group Participants

- recruit 25% more participants than needed
- ask participants to arrive 15-30 minutes before session starts
- contact potential participants 10-14 days before the meeting
- personalize written invitations one week before group
- follow-up with phone call day before group
- be sensitive to seasonal time demands (holidays, school)
- offer incentives to participants (let people know when and how incentives will be received)
- offer transportation and/or child care as needed

When offering incentives, Krueger (1988) suggests a three tiered incentive scale:

Level 1 -- \$15-\$25

Participants are relatively easy to locate. Limited eligibility criteria. Examples: Women age 50+ living alone.

Level 2 -- \$25-\$50

Participants must meet a number of eligibility criteria and may have limited time to participate. Examples: Nurses, health educators, clinic administrators.

Level 3 -- \$75-\$100

Participants must meet "precise" eligibility criteria, are underrepresented in the community, have very busy schedules, and expect significant compensation for their time. Examples: Physicians, corporate officers.

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... the [focus group] technique requires carefully trained interviewers (Krueger, 1988).

Moderator Skills and Characteristics

The richness of focus group results is directly related to the skill of the moderator. Since the nature of focus groups is rooted in group dynamics, a successful group is one in which the attitudes and ideas of participants are elicited and discussed. It is, therefore, very important to enlist a person who has certain personal characteristics and facilitation skills to serve as the moderator of the focus groups. A few of these skills and characteristics are listed in Table 1.1.

Table 1.1: Desirable Skills and Characteristics of Focus Group Moderators

Skills	Characteristics
creates a friendly atmosphere	good listener
asks questions without referring to the discussion guide	sense of humor
uses follow-up probes effectively	comfortable and familiar with group process
remembers the big picture	previous experience in working with groups
maintains mental discipline and concentration throughout the interview	adequate background knowledge of the topic being discussed
understands group dynamics	dresses similarly to participants
uses the "five-second pause" when conducting groups	uses language that is understood by the group
exercises a mild, unobtrusive control over the group	empathetic not sympathetic
able to sense the mood of the group	unbiased
communicates clearly and precisely, both in writing and orally	culturally sensitive
able to deal with unforeseen situations	

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The moderator must be careful not to make judgements about the participant responses. Phrases such as "that's a good idea" or "oh, do you really think that?" should be avoided. Body language that might communicate approval or disapproval of a person's comment should also be controlled. Head nodding should be limited. Use of short verbal responses and "value-neutral" gestures and comments are appropriate. Moderators should also avoid taking notes during the discussion. This should be a task of the observer.

The moderator must also be able to manage many different personality types within the context of a group interaction. Krueger (1988) identified the four types of participants listed in Table 1.2.

Table 1.2: Types of Focus Group Participants
• the expert • the dominant talker • the shy participant • the rambler

The moderator must be skilled in drawing out the "shy participant," and controlling the "dominant talker" and "the rambler." The contributions of "the expert" must be acknowledged, but also controlled in order that the "expertise," whether real or perceived, doesn't contaminate the discussion.

Untrained moderators

If limited resources force you to enlist untrained or inexperienced moderators, Krueger (1988) recommends that they participate in at least a 12-hour training program to prepare them to moderate the groups. Persons who are inexperienced at facilitating focus groups tend to be guilty of the following errors when conducting groups:

► Talks too much

Pauses during the discussion makes the inexperienced moderator feel it's not going well, that they need to keep the conversation going, rather than giving the

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The open-ended questioning, the use of techniques like pauses and probes, and knowing when and how to move into new topic areas require a degree of expertise typically not possessed by untrained interviewers (Krueger, 1988).

participants time to think and feel comfortable with the group.

► **Dominates the discussion with questions**

Persons who are new to a situation often tend to ask a lot of questions and are uncomfortable with silence. This is often the case with inexperienced moderators. They tend to keep asking the questions, rather than pausing to give the participants time to respond.

► **Moves too quickly from one topic to another**

Rather than thoroughly probing a participant's response to a question, persons who are inexperienced seem to have the need to move from question to question rather quickly, so that they will be sure to get through the entire guide. Inexperienced moderators often do not adequately engage all members of the group in the discussion, moving on to the next topic in the guide too quickly.

► **Spends too much time on one question or topic**

Inexperienced moderators, in contrast to above, sometimes spend too much time on questions that stimulate a great deal of discussion among participants, without revealing new information. This takes time away from other important questions which may uncover information previously unknown to the researcher.

A well designed training program with practice sessions can help to overcome these tendencies. Incorporating opportunities to role-play in the training is very helpful in preparing the moderator to interact with different participant personalities. Learning to feel comfortable with the "**five-second pause**" is also an important skill for focus group moderators. Pausing for five-seconds after a question is asked of the group enables the participants to gather their thoughts and prepare for sharing them. This lets the participants know that their

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responses are so valued that the group is willing to wait for them to be voiced. For some populations, a longer pause is necessary. Researchers working with Native American communities suggest that a pause of 10-12 seconds is often necessary to wait for a response.

Program staff and researchers as moderators

Many researchers and program planners want to be involved in the focus group, either through observing the groups or serving as moderator. By unobtrusively observing the groups, the researcher is able to witness the participants' comments and reactions. However, qualitative researchers warn not to have persons too close to the outcome of the focus group serve as moderators for several reasons:

- ▶ These individuals have a vested interest in the results of the group discussion and will not have the objectivity required of a focus group moderator.
- ▶ They are more likely to bring biases to the group and unconsciously sway the group one way or the other.
- ▶ They may not be trained as moderators.
- ▶ They are more likely to interpret the results in a biased manner.
- ▶ They may not have the appropriate characteristics (i.e. age, race, ethnicity, income, gender) to serve as moderator.

Assistant moderators

Using assistant moderators or observers (also referred to as recorders) to help the moderator during the focus group is strongly encouraged by qualitative researchers. The role of the assistant moderator includes:

- ▶ monitoring the audiotapes
- ▶ taking notes on non-verbal communication
- ▶ responding to unanticipated interruptions
- ▶ assuring a comfortable environment (heating, lighting, refreshments)
- ▶ assisting in the analysis at the end of the group

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As you will see in the section "*Analyzing the Results*," the assistant moderator may have a major role in preparing for the final report.

Recording and Observing the Groups

It is important that the group discussions are recorded in some manner either by audiotape or videotape. This enables the person responsible for writing the report to have a record of the discussion to refer to when analyzing the results of the groups. Before you decide to videotape the groups consider whether, for the particular audience you have recruited into the groups, this would interfere with the participants' ability to be candid or willing to disclose. This often depends upon the sensitivity of the topic to be discussed and the cultural characteristics of the participants.

When audiotaping the groups, be sure to use two high quality tape recorders. Use of two tape recorders reduces the likelihood that comments will be lost due to equipment malfunction. Always test the recorders prior to the groups to assure that they are in working order and that they are picking up sound from around the table at which the participants will be seated.

The Discussion Guide

The discussion or topic guide is the basis for the entire discussion the moderator will be facilitating with the participants. The guide must be prepared very carefully and with input from the researchers and the moderator.

It is suggested that planning for the guide begin with a brainstorming session with all parties who have interest in the results of the focus group. Start with defining the objectives for the session, and then identifying potential questions. The discussion guide should begin with a brief introduction to the study, explained in very neutral terms. For example, a focus group designed to determine women's attitudes and beliefs regarding screening mammography can be described as a "discussion about women's health issues." It is also helpful to explain what a focus group is and why the participant's input is important. It should be stressed that there are no right or wrong answers and that all thoughts and opinions are welcome.

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The discussion guide should start with general questions and then move to more specific ones. The general questions should help to "warm-up" the group -- to make them feel comfortable and establish rapport. Questions should be sequenced by their relative importance to the research agenda. Those of greatest importance should be placed early, near the beginning, after the general questions. Placing important questions first will help assure that sufficient time is given to these questions. Sometimes questions left for the end of the discussion are rushed through because too little time is left. Assure sufficient "warm-up" before delving into sensitive issues.

It is important to have an experienced moderator or qualitative researcher review the discussion guide and the probes that are to be used. This expertise will help to assure that the flow of the questioning is adequate, and that the manner in which the questions are asked will obtain the types of information you desire. Experienced moderators are also very helpful in determining appropriate probes to use with certain questions in order to obtain richer responses from the participants.

The discussion guide should be used in a pilot test with eligible participants. If there are no major changes in the guide, the results of this group can be included in the final report. During the pilot, you should pay attention to:

- | | |
|--|-----------------------------|
| ▶ wording and flow | ▶ ordering of the questions |
| ▶ ability of the group to understand the questions | ▶ room arrangement |
| ▶ effectiveness of probes | ▶ group composition |
| | ▶ moderator procedures |

At the end of the pilot group, turn off the tape recorder, announce that the session is over, and seek comments from participants. This will help you to learn how the discussion flowed for the participants. They can make helpful suggestions to benefit subsequent groups.

A sample discussion guide used for conducting focus groups with women on barriers to breast and cervical cancer screening can be found in Appendix B. Table 1.3 provides a typology of questions that can be included in the discussion guide.

Table 1.3: A Typology of Focus Group Questions	
Type of Questions	Purpose
Main research questions	Focus discussion on issues directly related to the purpose of the session. Exactly how you are going to ask these questions should be thought out beforehand.
Leading questions	Useful for carrying a discussion toward deeper meaning and are especially useful if the group seems hesitant to pursue it. Formulate the questions using the groups words and ideas and by asking, "Why?"
Testing questions	Used to test the limits of a concept. Use the group's words and ideas to formulate the question, this time feeding the concepts back to the participants in a more extreme, yet tentative form, as though you may have misunderstood. For example, "are you saying...?"
Steering questions	Used to nudge the group back onto the main research questions, following its frequent excursions into what it wants to talk about.
Obtuse questions	Often the discussion will go into territory uncomfortable to the group. To further pursue topics into such areas, you need to back the questions off one level of abstraction, allowing the group to discuss other people's reactions or opinions, not necessarily their own: "Why do you suppose somebody would feel this way?"
Factual questions	Questions that have a factual answer and permit the group to answer without personal risk. These questions can be useful for neutralizing emotionally charged groups or discussions.
Feel questions	Used to ask for opinions surrounded by personal feelings. Feel questions ask participants to take risks and expose their personal feelings. They are the most dangerous and most fertile of question types. The rule to remember here is that every person is entitled to his or her feelings, and no one else can disagree with or discount them, though many will try.
Anonymous questions	Used to get a group talking, comfortable with each other, or refocused on a key question. They generally take the form, "Please take the index card in front of you and write down the single idea that comes to mind regarding this issue."
Silence	Often the best question is no question. Many group leaders tend to fill in every void in the discussion. Simply waiting for a response allows those who are a little slower or uncertain to formulate their ideas.

(from: Wheatley & Flexner (1988), in Shedlin, MG; CDC Workshop Handouts, 1992)

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Analyzing the Results

Depending on the methods chosen to document focus group sessions, there may be extensive written material to be analyzed. Krueger (1988) suggests that information from the following resources be included in the focus group analysis:

- ▶ post-session summary reports
- ▶ audiotapes
- ▶ discussion guide
- ▶ demographics of participants
- ▶ transcripts of discussion

Generally, it is best if the person who moderates the groups or the assistant moderator analyzes the data and drafts the report. The moderator and the assistant moderator were able to observe the discussion and the interaction among the participants. Recorded observations of the nonverbal communication that took place during the group is an important component to be considered when analyzing the results. If an assistant moderator was not involved and if the moderator is unable to analyze the groups, it is important that he or she discuss the groups, including the nonverbal communication that took place, with the person who will be responsible for this task.

Skills required for analysis and report writing are different from those needed to moderate groups. A moderator may not possess both types of skills. It is important that this is considered when planning the groups in order for arrangements to be made early regarding who is to draft the report.

A post-focus group meeting of the moderator, assistant moderator, and the report writer can be extremely helpful in analyzing the results of the group. Briefly summarizing the group's comments and jotting down key points which were raised by the group immediately after the session is over will assure that these points are not overlooked in the results.

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The researcher must filter out preconceptions, expectations, and personal opinions and tune into the signals being transmitted by participants (Krueger, 1988).

Analyzing focus group data can be a difficult process because of the diversity of participant responses and the amount of information to be reviewed. As with conducting the focus groups, the researcher or program planner should keep in mind the issue the groups were designed to address during the analysis stage. This will help to keep the analysis on track and result in a useful report. Data analysis is generally performed by reviewing the discussion transcripts, observer notes, and the videotape, if available. The researcher looks for themes and trends in participants' responses. Comments made must be placed in the context and perspective of the participants. Strongly held opinions must also be noted. This information forms the structure of the report, giving the reader a good understanding of similarities and unique differences among focus group member responses.

Analysis of focus group data can be accomplished by using both "inductive" and "deductive" techniques. Inductive techniques involve looking for themes and trends which emerge from the group discussion. Using deductive techniques, the researcher is guided by a conceptual or theoretical framework in seeking themes in the data.

One method of deductive analysis involves standardizing and coding the different data sources and using a technique such as "domain and taxonomic analysis" (Spradley, 1980). In this type of analysis, a standardized protocol is developed to look for specific factors of interest identified prior to the focus group as a guide (e.g., "x factor contributes to a positive perception of mammography screening"). Using this protocol the researcher looks for comments and non-verbal indicators from the data that "fit" the factors of interest. These factors are then grouped into categories of factors ("domains") and hierarchies of responses ("taxonomies"). Further analysis of the factors identify how they are similar or related to one another, as well as where they are different and, at times, extreme opposites. These groupings eventually determine themes and sub-themes.

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The resulting taxonomies and themes can answer the research areas of interest, such as "In what ways do low-income African American women (in the focus group) respond to the idea of mammography screening?" The taxonomies can identify categories of feelings, family and cultural history and knowledge levels that could lead to a positive or negative behavior toward mammography screening.

There are ways to organize data to facilitate and structure analysis using specialized computer software packages such as "Ethnograph" and "Nota Bene." These data management packages assist the researcher to identify repeated comments and observations and cluster them into similar groups. The researcher then works with the identified categories and their relationships to complete the analysis process.

Writing the Report

When deciding upon what approach to take in writing the report, it is important to consider how the report will be used and by whom. Including a description of the planning and recruitment efforts in the report is also very helpful to other program planners and researchers. In general, there are three types of focus group reports:

- ▶ A brief oral report that highlights key findings, beginning with the most important.
- ▶ A descriptive report, either oral or written, that provides a summary of participants' comments and observations.
- ▶ An analytical report, either oral or written, that identifies key trends or findings from the participants' responses. This report can include illustrative quotes from the focus group discussion.

All reports must be based on a thorough analysis of the discussion transcripts and other resources described previously. The first two reports described above are primarily descriptive in nature. They are summaries of the similar responses and trends that were noted during

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the focus group sessions. The analytical report provides key findings and trends in greater detail with interpretation.

As noted previously, regardless of the method of analysis that you choose, it is extremely important to consider your audience as you organize the results of your analysis into a report. Keep their needs in mind as you decide which type of report would be the most effective and useful.

The Budget

The cost of conducting focus groups can vary widely depending upon a number of factors including location, contracting with a market research firm, and the decision to videotape the focus groups. It is possible to spend up to \$2,500/group. Items to consider when developing your budget are listed below:

- ▶ Moderator fees
- ▶ Participant incentives
- ▶ Audio equipment rental
- ▶ Audiotapes
- ▶ Audiotape transcription
- ▶ Recruitment costs
- ▶ Videotaping
- ▶ Travel (for staff and participants)
- ▶ Childcare for participants
- ▶ Report writing and duplication
- ▶ Refreshments for participants
- ▶ Site rental

You may be able to reduce some of the cost by using many of your own institution's resources, including personnel and equipment. Use of inexperienced moderators can also reduce your costs, but often at a cost to the quality of information to be derived from the focus groups.

Incentives for participation can often be provided by obtaining donations from outside sources including neighborhood grocery stores or transportation services.

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Ideas for possible incentives (depending upon your audience) are provided in Table 1.4. Be sure to determine what incentive is most important for your audience prior to recruitment.

Table 1.4: Participant Incentives

Cash Transportation vouchers Grocery coupons Gift certificates from local merchants Gift "bags" from local merchants Lottery tickets Presentations by an "expert" on a health topic

Participant recruitment also entails certain costs, and depends upon the strategy you have selected to use and your resources. A market research firm may charge \$700 - \$1000 per group to recruit 10-12 participants. The variation in fees depends upon the difficulty in locating appropriate participants and the regional differences in market research fees. You may be able to use your own staff to recruit participants, but remember - this can be a very labor intensive endeavor. Don't underestimate the time you need to commit to this effort.

The chart on the following page outlines a few of the costs that one project incurred in conducting focus groups with low income women from different cultural groups.

Breast and Cervical Cancer Research Project Breakdown of Approximate Focus Group Costs

Moderator:

Two moderators were hired to facilitate four different focus groups. Cost for moderator varied depending upon training and experience. Each moderator also broke down her services a little differently. Travel expenses (airfare, hotel, meals) should also be included.

- ▶ Moderator 1:
\$200/day -- this included two groups per day, travel time, preparation, and report writing.
- ▶ Moderator 2:
\$400/group -- this included facilitation of group only. Other costs broke down as follows:
 - \$1,000 preparation and finalizing discussion guide
 - \$ 200 report writing (approx. for one group)

Note: Use of inexperienced moderators, graduate students, individuals from the community would reduce costs. May be able to pay on an hourly basis.

Tape transcription:

- ▶ \$30/hour -- for transcription and translation of Spanish tapes
- ▶ \$12/hour -- for transcription of English tapes

Note: One 2-hour English tape required approximately 4-5 hours to transcribe.

Participant recruitment:

- ▶ \$800/group -- cost of using a market research company for recruiting 10-12 participants per group

Site rental:

- ▶ \$50/group -- provided as a "donation" to community center and church which permitted use of their facilities
- ▶ \$300-1000/day -- focus group facility with viewing room

Equipment rental:

- ▶ \$60/day -- included 2 tape recorders, microphones, mixer, tapes, delivery
- ▶ \$40/day -- transcription unit

Incentives:

- ▶ \$40/participant -- cash was provided
- ▶ \$10/participant -- cost of refreshments

Travel:

- ▶ varies by location and need (staff and participants)

Childcare:

- ▶ provided by program staff

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Questions to Consider in Designing Focus Groups

The following are questions to consider when designing and implementing focus groups. Responding to these questions prior to initiating the groups will help to assure that you obtain the information needed to design your intervention.

- ▶ Determine the objectives

What is your research question?

What information do you need to obtain from the participants?

How will the results of the focus groups be used?

- ▶ Describe characteristics of focus groups based upon defined purpose

Who should be participating in the focus groups?

What is the eligibility criteria?

- ▶ Decide on the budget

How much money do we have to spend on focus groups?

What are our internal resources?

Do we have external resources that we can tap into?

- ▶ Recruit participants

How should we recruit our participants?

Where do people fitting our eligibility criteria live, work, play?

Are there people on staff who can do the recruitment or do we need to hire a market research company?

Would a market research company have access to the community we are interested in reaching?

- ▶ Hiring a Moderator

What are the characteristics of the moderator we need?

Do we have the funding to hire a trained and experienced moderator?

If not, where can we find someone not directly affiliated with the program who can be trained to conduct the groups?

Who will design and conduct the moderator training?

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► Developing the discussion guide

Who has a stake in the outcome of the focus groups?

Who will design the discussion guide?

How long should it be?

Does the discussion guide need to be translated into another language?

Do we have a process for translation?

What are the most important questions to be asked?

How will the responses of the participants be recorded?

► Conducting the focus groups

Where will the groups be held?

How will the responses of the participants be recorded?

► Analyzing results and interpreting findings

Who will write the report?

Who will receive copies of the final report?

How will the results be used?

◆ **Section 2: Breast and Cervical Cancer Programs:
What Focus Groups Have Found**

The Methodology

The sample for this review includes reports of focus groups on breast and cervical cancer screening obtained by the AMC Cancer Research Center from various organizations. Reports from 22 studies were received, representing the results of 133 focus groups conducted in 1991 or 1992. Organizations who submitted reports included 9 state health departments, 4 cancer centers, 4 universities, and 2 national organizations (Appendix C).

The reports reviewed for this paper varied in their length and level of detail. Most were prepared using content analysis. In one case, transcripts from the focus group discussions were received and reviewed. In another, findings from five focus groups were summarized into three pages by the researcher specifically for use in this report.

The purpose for conducting the focus groups varied by study. In general, all studies were intended to identify barriers to breast and cervical cancer screening as perceived by the specific target audience. The information derived from the focus groups is intended to be used by either program planners in designing educational programs for their specific audiences, or by researchers to expand the current body of research knowledge.

Focus Group Composition

Focus group reports represented the attitudes and perceptions of diverse audiences of women. An overwhelming majority (78%) of the groups were conducted with women living in urban areas (Table 2.1).

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Over one quarter (26%) of the groups were conducted with African American women, whereas only 4% of the groups involved Native American women (Table 2.2). Low income populations were the groups most often involved in the studies, comprising 46% of the focus groups reviewed (Table 2.3). However, 31% of the focus group reports did not specify the income of their respondents.

Table 2.1: Focus Group Composition -- Geography

Geography	Percentage of Groups
Urban	78%
Rural	14%
Unspecified	8%

Table 2.2: Focus Group Composition -- Race/Ethnicity

Race/Ethnicity	Percentage of Groups
African American	26%
White	22%
Hispanic	19%
Native American	4%
Mixed groups	9%
Unspecified	21%

Table 2.3: Focus Group Composition -- Income

Income	Percentage of Groups
Low	46%
Middle	14%
Mixed	16%
Unspecified	31%

The age of the respondents ranged from 15 to 80 years old. A majority of the groups were comprised of women over the age of forty. The mix of ages within each group also varied. For example, some reports stated that their groups involved women between the ages of 60 and 65,

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while others stated that their respondents were women over the age of forty, without providing a precise breakdown of the respondents' ages. It appeared that few focus group participants were selected on the basis of their breast or cervical cancer screening history. Most women had had at least one mammogram in their lifetime. Others in the focus groups had never had one. Few groups were stratified according to the participants' screening history.

Basis for Comparison

The reports were reviewed with consideration given to women's responses to the following items of interest:

- ▶ Attitudes toward health
- ▶ Sources of health information
- ▶ Attitudes toward cancer and early detection
- ▶ Attitudes toward breast and cervical cancer
- ▶ Barriers to breast and cervical cancer screening
- ▶ Interventions to encourage more women to be screened

Not all of the groups were asked the same or similar questions. However, a majority of the groups did discuss the women's attitudes toward health, cancer, and early detection, specifically including breast and cervical cancers. Barriers to breast and cervical cancer screening were explored in nearly all of the groups. Less frequently asked were questions which related to the women's sources of health information and their suggestions regarding how to motivate women like themselves to be screened.

As with some qualitative research, there are limitations to how information derived from focus groups can be used. Small sample sizes and respondents who are not representative of the total population make generalization inappropriate. However, focus groups can be utilized in the development of hypotheses, to test program concepts, and to pretest educational materials.

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The depth of the comparison analysis in this section is limited by the diversity of the focus groups' intent and composition. Reports reviewed provided little detail regarding the size of the groups, moderator characteristics, and the recruitment process utilized, including screening criteria. A number of respondent characteristics were also vaguely reported, including adherence to mammography guidelines, ethnicity, and income. Detailed comparisons were, therefore, not possible. In general, however, enough information was provided to allow for the identification of certain themes and areas of divergence among the different populations studied.

Results of Comparison

Attitudes Toward Health

Personal health was seen as very important to women in all of the groups. The specific health issue of concern varied somewhat among population groups, with most older women being concerned primarily with various chronic diseases. Older women were also concerned about becoming a "burden" to their families, and sought to keep themselves healthy for their husbands and children. Many Hispanic women reported that their greatest fear was that illness would prevent them from taking care of their families. Hence, they would seek to keep themselves healthy for their families' sake. "Quality" of life was seen as more important than length of life by many older women in a few of the groups.

A few women in the Hispanic and the African American groups reported that they sometimes use "folk remedies" to treat certain illnesses.

"... I used to have swelling, my legs...and my sister said take five cherries a day or cherry juice...and I tell you my legs went down."

"You take the 'anamu' root, and the ripe coffee leaf and a herb called verbena, this cured my daughter's asthma, in my country."

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In addition, some of the groups of African American and white women reported that a positive attitude was important in the maintenance of good health.

Sources of Health Information

Groups that were asked to identify sources of health information had very similar responses (Table 2.4). Information sources mentioned most frequently included physicians, television, brochures, and newspapers. Some Hispanic women reported that they did not feel that the mass media was a "credible" source of information. Persons who have had a health problem, such as a person who had experienced cancer, were also mentioned as sources of information. This may include a mother or sister who has had the health problem, or a person who knows someone with the problem. Many women reported that the most credible sources of information were people with whom they could personally identify.

Table 2.4:
Commonly Cited Sources of Health Information

- Physicians
- Television
- Brochures
- Newspapers
- Family/friends

Some of the African American and white women reported that they use lay medical books as information sources. A few persons mentioned, when specifically probed, that they would seek information from organizations that have information "hotlines" such as the Cancer Information Service or the American Cancer Society. Hispanic women reported having little experience with "hotlines." In addition, new Hispanic immigrants reported that they did not know where to go for health information.

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Attitudes Toward Cancer and Early Detection

Among most of the groups, cancer evoked fear in women who were asked what they felt when they thought about cancer. Many women also equated cancer with suffering and death. However, most of the focus group respondents did believe that cancer could be cured if it were detected early, depending upon the type of cancer. Yet, in one study of older persons (60-75 years old), few understood the benefits to early detection.

Pervasive across many groups was the belief that a positive mental attitude is important in overcoming disease and illness. Women reported that one's spiritual health has influence over her physical health.

In many of the groups, a strong belief in God was evident. Several women in various focus groups said that cancer was "God's will." Some rural African American women believed that cancer was sometimes a punishment from God. Hence, diagnosis of cancer had a tremendous stigma surrounding it. The belief that cancer is often God's will was most prevalent among Hispanic women, including women of Mexican and Puerto Rican origin (Table 2.5).

**Table 2.5: Attitudes Toward Cancer
Among Different Populations**

Attitude	Population
Fear	All
Causes suffering	All
It's God's will	Hispanic/Rural African American

Knowledge of and Experience with Breast and Cervical Cancer Screening

There was tremendous consistency across focus groups in the women's knowledge regarding breast and cervical cancer screening. Most women, except for those in the new Hispanic immigrant groups, were at least somewhat knowledgeable about mammograms and their effectiveness. They were able to explain that

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mammograms were x-rays of the breast that could detect cancer early. The procedure was vaguely described by the women who had had a mammogram previously.

Beliefs regarding who is at risk for cancer varied somewhat across the different groups. Some older respondents believed that younger people were at greater risk than older people. In addition, they didn't believe that everyone needs to be "checked" for cancer. Most women were also not sure of the age that women should begin having mammograms nor how often. Family history of breast cancer was the most frequently reported true risk factor. Several other factors were erroneously reported by many women in all groups as being risk factors, including: trauma to the breast, breastfeeding, and breast size (Table 2.6). Respondents described all women as being at risk for breast cancer.

**Table 2.6: Common Misconceptions
Regarding Cancer**

Breast Cancer

- Caused by trauma to the breast
- Age not a risk factor
- Risk influenced by breastfeeding
- Breast size influences risk

Cervical Cancer

- Pap tests can detect sexually transmitted diseases, ovarian cancer, and estrogen levels

Most of the women involved in the focus groups reported having had one or more Pap tests, although they did not necessarily see themselves as personally at risk for cervical cancer. They viewed the Pap test as being an important part of every women's routine care. Most said all women should have one every year. The recommended frequency of having a Pap test was not known to some of the women, nor was the age at which a women should start having one.

When asked what a Pap test could detect, women responded with a long list including estrogen levels, sexually transmitted diseases, ovarian cancer, and uterine

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cancer. Risk factors for cervical cancer, such as multiple sexual partners and having sex when very young, were reported by the women.

Some of the Native American women interviewed reported that they were uncomfortable with being examined by a male physician. In contrast, some Hispanic immigrants stated that they were more comfortable being examined by a male physician than by a female physician. In another focus group of Hispanic women, it was reported that they preferred female providers. Older women preferred being seen by an older physician, which creates difficulties when the older physician retires. Young male physicians made some of the older women in the focus groups feel uncomfortable.

Barriers to Screening

Barriers to screening were very similar across the different focus groups. Common barriers reported include:

- fear that cancer would be found
- embarrassment
- lack of knowledge regarding the need to have the procedure
- discomfort of the Pap test

Many women, especially those in the older age groups, held the attitude that *"If it ain't broke, don't fix it."* This statement reveals a lack of understanding of the screening concept, and a lack of perceived vulnerability.

Transportation wasn't identified as a major barrier by any of the women, as most knew where they could get a mammogram and were able to get to that location.

Finding the time to have a mammogram was mentioned by women in some of the Hispanic and African American groups. Many women found it difficult to take time from work to go to the physician.

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Spanish-speaking Hispanic women reported that the lack of health care providers who speak Spanish is a major barrier to receiving health care. Some women will bring a family member with them to serve as an interpreter at the doctor's appointment. This often exacerbates the problem of finding the time, as it impinges upon another person's schedule. One woman said that she took her child out of school in order to have him interpret for her. This added burden of having to find one's own interpreter serves to strengthen the deterrents to having a mammogram.

Cost was reported by at least a few women in most groups as being a potential barrier. Many women, however, stated that cost would not be an inhibitory factor if they felt that they really needed to be screened. Several low income women with little or no health insurance expressed concern not for the cost of the screening procedure but for the treatment should cancer be diagnosed.

"Even if they said, 'You go and get a mammogram because you need one,' and I go get one, what if I have cancer? Then what? I still don't have any money and no insurance. So wouldn't it be better if I didn't know about it?"

Several women, particularly among the Native American groups, were concerned about mammograms increasing a woman's risk for breast cancer. Exposure to radiation was thought to make a lump, if present, grow larger, and therefore less amenable to treatment. Women were also concerned that a mammography technician who is too rough may cause a bruise. Some women believed that this bruise may then lead to cancer.

Physician distrust, which was prevalent among some African American groups and a few white groups, was identified as a barrier. Women did not trust that their physicians were recommending a screening examination for their welfare, but rather to gather greater income.

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Many older women, across all ethnic groups, held to the belief that "If they're 65 and don't have [cancer], they're not going to get it." Most women reported that their religion had little or no influence over their screening behavior. However, a number of women, primarily rural African American women and some Hispanic women, shared their belief that God can cure all ailments and that it is not always necessary to seek health care.

Messages and Delivery Channels

An overwhelming majority of women across the focus groups stated that testimonies of role models, or persons who had either experienced breast cancer or mammography, would be most effective in influencing women like themselves to be screened for breast cancer. Many women also suggested that television may be an effective channel to reach a large number of women regarding mammography. Although many of the Hispanic women suggested using television as an intervention medium, they also stated that some women do not watch television because they are too busy. A few women mentioned that public television would be a credible source of information.

Women felt that messages intended to educate women about mammography or Pap tests should be clear and to the point. They should also inform women as to what to expect when they are to have either procedure. Messages should also be reassuring, stating that women can obtain "peace of mind" when they are screened for cancer -- letting them know that they are in good health.

◆ Section 3: Qualitative Research Among Very Low Income Populations

Modifying the Methodology: Working in Very Low Income Communities

As suggested in Section 1, certain modifications may need to be made in traditional qualitative research methodology when working with very low income populations. Market and behavioral researchers have observed certain characteristics among some low income communities that may influence the effectiveness of traditional qualitative research methods. These characteristics are presented in Table 3.1. Keep in mind that these characteristics have been observed in *some* low income communities, regarding *some* individuals with low incomes. Not all persons who are poor or living in low income communities are the same. It is recommended that researchers are sensitive to the potential for these characteristics when working within low income communities in order for them to be addressed, when necessary.

**Table 3.1: Potential Characteristics
of Low Income Audiences**

- suspicious of research
- suspicious of "the establishment"
- not accustomed to being asked for personal opinion
- cautious of revealing themselves
- tend to be timid, lacking in self-confidence
- easily dominated in a group discussion
- more likely to respond to questions as they feel they are "supposed to"
- less likely to volunteer for research
- transportation may be a barrier to participation

It is important to consider the above characteristics when conducting qualitative research, especially using focus groups. The efficacy of this technique depends upon the candor of the individual and the dynamics of the group interaction. Individuals need to feel a sense of comfort and trust in order for qualitative research techniques to be effective.

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Qualitative Research Among Low Income Populations

Few articles have been published on conducting qualitative research among low income populations. Many of the focus group reports reviewed in Section 2 reported that they involved individuals with low incomes in the research. However, the focus group reports did not discuss the methodologies that were used for recruitment nor specifics on how the research was conducted.

This section of the guidebook seeks to illuminate the recruitment and implementation issues relevant for working within low income communities. Described are the experiences of commercial market research firms, as they were reported to the AMC Cancer Research Center (AMC), and AMC's experiences in planning and implementing focus groups among low income women living in Denver, Colorado.

Experiences of Commercial Marketing Firms

In order to identify what techniques commercial marketing firms are using to develop market communication strategies to reach the low income consumer, AMC conducted telephone interviews with over forty individuals affiliated with selected organizations conducting research in this area. The organizations or businesses were selected based upon whether the product or service that they provided was in wide use by low income consumers. A list of such products and services was generated through the use of marketing databases that correlate purchased products and the consumer's household income.

The interview was unstructured to allow for maximum flexibility in discussion. One individual conducted all the interviews to provide for consistency in delivery and to reduce any confounding biases.

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Potential Recruitment Sites

- social service offices
- job centers
- neighborhood block clubs
- movie lines
- shopping centers
- food markets

Using Focus Groups:

Recruitment Strategies

Respondents reported that many of the characteristics listed in Table 3.1 may inhibit some people from participating in focus groups. In addition, recruitment of low-income participants usually takes more time than the recruitment of participants in higher income categories. Generally, the recruiter needs to expend greater effort to identify and locate eligible low income individuals who are interested in and willing to participate in the study. Over-recruitment is necessary as the number of "no-shows" is frequently higher among low-income participants as compared with the general population.

Respondents reported that recruitment of low-income participants can be more efficient if conducted through local non-profit organizations such as churches, women's centers, government sponsored daycare centers, and community clinics. It has been found that recruiting through familiar neighborhood organizations is less intimidating than using strangers to recruit, even when the recruiters are of the same ethnic background as the participants.

Location of Interviews

Conducting the focus groups in the participants' neighborhood was generally recommended to avoid the transportation barrier. For some participants, even when the focus group is conducted in their neighborhood, transportation may be difficult. Providing transportation, through the use of a van or by providing bus or taxi vouchers, can be an effective means to overcome this barrier. Some researchers reported using a mobile van as a site for conducting the groups.

It is advantageous to conduct focus groups in familiar surroundings like schools, churches, community clinics, or public libraries. The selection of the appropriate location should be based upon where the participants feel most comfortable and at-ease.

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Moderator Characteristics

Representatives of commercial marketing firms reported that the characteristics of the moderator conducting the focus groups are very important to consider. In particular, it is vital that the moderator be of the same racial and ethnic background as the group's participants and sensitive to the economic status of the participants. It is not appropriate for the moderator to come to the group dressed in a manner that might be interpreted by the participants as implying that the he or she is "better than they are" or has more "authority" than they do.

Other Techniques:

Other qualitative research techniques that can be useful when working within low income communities were suggested. These include:

- Ethnographics
- One-on-one and one-on-two interviews
- Small groups (triads, quads)
- Projective techniques
- Value-centered interviewing

Ethnographics

Ethnographics is one of the newest marketing techniques derived from a sub-discipline of anthropology. This technique entails going into the subjects' milieu, in the home and social settings, to make on-site real-life observations of their life setting (e.g., the food pantry, medicine chest, dinner preparation, conversations, interpersonal interactions). This technique yields information that either is not observable except in the home, or not talked about on the street or in a focus group.

One caveat in using ethnographics was mentioned by some of the respondents. Certain cultures regard a visitor in the home with a high level of respect that would bias the results of using ethnographics. For example, a study subject would be likely to prepare the home before the researcher is to visit, and would be strongly inclined to

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try to please or impress the interviewer. In such cases, these in-home techniques are not recommended unless interviewers who are familiar to the subject and his or her family are used.

One-on-ones and One-on-twos

Interviews conducted with one or two subjects are referred to as *one-on-ones* or *one-on-twos*, respectively. In one-on-one interviews, especially those conducted in the home, persons who are very timid and lack self-confidence can be encouraged to be candid and share their thoughts and feelings. In-depth one-on-one interviews, conducted either at central locations or in the home, tend to eliminate the influences of peer pressure and group biases that can occur among larger focus groups.

A similar technique involves research conducted in shopping centers frequented by members of the intended audience. People can be recruited to respond to on-the-spot interviews while doing their shopping. This technique tends to be less expensive than conducting interviews in the home.

One-on-twos were described by some of the commercial marketers as highly useful among teenagers. Adolescents have a tendency to play off one another which can be advantageous to a skilled interviewer. A one-on-two technique used for a community action organization discovered patterns of cooperation with drug dealers among children 9-11 years of age that would not have been uncovered without the interactions among the paired respondents.

One-on-ones and one-on-twos are highly useful if there is a need to use pictures and actions to communicate. For example, one company wishing to strengthen its market in the rural South used pictograms to represent various responses, asking the respondent to indicate the pictures that best represented their responses.

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Small Groups (triads, quads)

Group discussions involving three, four or five participants instead of the standard focus group number of eight or ten represent a technique which, though more expensive on a per respondent basis, often offers a better environment in which to overcome some of the barriers to communication among low income populations. With this technique, it becomes extremely important to closely match respondents on gender, age, and ethnicity. Smaller groups help to ensure that each participant has an opportunity to share his or her ideas and thoughts on a subject. It is generally easier for the moderator to facilitate discussions among smaller groups, especially when seeking to elicit comments from people who tend to be shy or uncomfortable in larger groups.

Projective Techniques

Modified projective techniques are being used to elicit subtle associations that are otherwise unlikely to be articulated by research participants. Some of these techniques would seem to be useful in designing messages on sensitive subjects or on subjects that have a strong emotional or hidden cultural barrier. Examples of projective techniques were shared by two of the respondents.

"Self-structured sorting": A soap manufacturer brought in 30 detergent packages and asked groups of low income consumers to sort them any way they pleased and to explain why they grouped them in a particular way. From the result they learned much about what was really important to the target group about the product category of interest.

"Product Personality Association": The researcher named a few items in a shopping cart and asked the respondent what comes to mind about the person pushing the cart, or what else the respondent would expect to find in the cart.

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Value-centered Interviewing

Value-centered interviewing is a procedure developed to explore the relationship between products and personal values and emotions. The procedure involves inviting participants to talk about a topic through a series of steps that takes them increasingly deeper into how that topic relates to their personal values.

The study participant is asked to begin talking about the product in a very superficial way, e.g., to describe the product and its attributes. The participant is then asked to describe any personal implications these attributes might have for her, and then to discuss why these implications are personally important to her. At the end of this process, the participant is talking about her personal values and emotions as they relate to or are affected by the product or issue.

The underlying theory is that unless a way can be found to tie the issue to these personal values, no behavior change can be expected. For example, smokers can generally recite the negative impacts of smoking on themselves. But when they are asked to tie smoking to personal values important to them, either there is no link to those values, or the personal value linkage that does exist reinforces smoking. Thus, when asked to describe the personality of one who stopped smoking, a smoker characterized the quitter as someone who "doesn't care about personal freedom." This leads to an exploration of what makes personal freedom so important.

Value-centered interviewing is a device to discover those links between personal values of a group of people and a product or issue. It has been applied to low-income groups, teenagers, Hispanics and others on behalf of products and health education in the United States and other countries. According to the researchers who developed this technique, it has been especially effective in areas where the issues are not well articulated, and where the topic is particularly sensitive, or when it is difficult to elicit comments from the participants.

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Value-centered interviewing can be done one-on-one or in small groups of 5-6 participants. The process takes approximately 1½ to 2 hours, and specially trained interviewers are needed.

Summary

In summary, the respondents agreed that effective qualitative social marketing research among the poor requires a mixture of sound applications of standard research approaches (e.g., focus groups) with innovative techniques designed to get below the surface (e.g., in-depth one-on-ones, triads).

Experience of the AMC Cancer Research Center

The AMC Cancer Research Center conducted seven, two-hour focus groups among very low income, African American, American Indian, and Hispanic women living in the Denver area. Having a particular interest in maintaining recruitment among the poorest of these ethnic groupings without targeting homeless women, the methodologies standardly employed by consumer research groups, ie., computerized respondent lists or newspaper advertisements, were not utilized. Because the women for each group were recruited from the same community, they were more likely to know one another than if recruited from a broader geographic area. This familiarity with others in the group deviates from standard focus group methodology in which it is recommended that the respondents not know one another.

The utilization of inexperienced moderators to conduct the groups also deviated from accepted standards of focus group methodology. Although the researchers are confident that the information elicited by the moderators was extremely valuable, more in-depth information could have been derived if trained, experienced moderators were used for all groups.

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Recruitment Process

Low income communities and organizations that serve them were initially identified. Informal meetings were arranged with community agents, or community leaders to discuss the purpose of the focus groups, the criteria for participation, the projected timetables for each group, as well as to identify accessible, culturally familiar locations in which to hold the focus groups. Community agents contacted for possible identification of prospective participants included the following:

- ▶ a senior coordinator at an American Indian community center
- ▶ the director of an American Indian health services center
- ▶ social service coordinators at a Catholic services center serving Hispanics
- ▶ the pastor of a Catholic church serving Hispanics
- ▶ the pastor of a United Methodist church serving African Americans
- ▶ the social service coordinators of agencies within an African American community

For some communities, several initial contacts were made with community agency directors to determine where the largest pool of prospective participants might be found. Agencies and communities were eliminated if they had participated in breast cancer screening projects within the past year, or if they were involved in any formative cancer control studies of the state health department. This was done in order to limit the chances of recruiting women who had previously been involved in focus groups. Community agents were asked to tell prospective participants that the focus of discussion would be women's health issues and, if they had any specific questions, they could refer them to the recruiters, who would be contacting them later. The lists of prospective participants generated by the community agents were then given to recruiters for more detailed interviewing and follow-up by phone.

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Cultural Sensitivity of Recruiter

Women of the same ethnic background as the focus group participants were selected to be recruiters in order to maximize cultural sensitivity to the identified participants. The recruiter for the Hispanic groups spoke Spanish fluently. Recruiters interviewed prospective participants, asking them detailed questions regarding income levels, household size, age, general health status, and previous history of mammography. All prospective focus group participants were told how their names were obtained and the name of the community agent who made the referrals. Personal one-on-one interviews with women at community center meetings worked particularly well in recruiting Hispanic and American Indian women. If eligible, the women were told that they would receive monetary compensation for their participation and that food would be provided. Where appropriate, ethnic specific foods were served, such as pan dulce for the Hispanic groups, and fry bread for the American Indian groups. Transportation to and from each site was provided for participants who required it. Child care arrangements were facilitated for several participants. The recruitment process took between two and six weeks from initial contact with community agents to date of the scheduled focus group. All groups were held within the targeted communities.

Contacting Potential Participants

Some differences were encountered in the recruitment process for each population. An inordinate number of women needed to be contacted in order to recruit the desired number of participants for each group. The Hispanic group required that one and one half times the number of women to be recruited were contacted, whereas the African American groups required that seven times the number of women needed for adequate group size be contacted. The number of women contacted for the American Indian groups fell in between the other two populations, with twice as many women than needed being contacted by the recruiter. The higher response among the Hispanic women may be due to the active involvement of the community agent. This woman initially contacted all prospective Spanish-speaking

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women prior to the recruiter making any initial contact. The community agent who assisted with the recruitment among American Indian women also made initial contact with the prospective focus group participants.

The recruiter for the African American groups experienced the most refusals to participate, which in part may be due to: 1) distance from the targeted community and less chance for one-to-one, direct interaction, 2) relatively higher rates of adherence to mammogram screening guidelines, and 3) more resistance to and suspicion of the research process. The recruiter also had difficulty contacting 18% of the women whose names were on her list due to wrong telephone numbers, disconnected phone service, or no answer.

It is generally agreed that in order to obtain an adequate group size, one should over-recruit by at least 50%. Therefore, if a group of 10 women is desired, the recruiter should confirm participation of at least 15 women. This is to accommodate for no-shows and cancellations. In this study, over-recruitment was not necessary, as nearly all of the women who committed to attending the focus group participated. In a few instances, women brought a friend who was also interested in participating. If eligible, these women were included in the group.

Moderator Characteristics

The moderators varied in their skills and experience in conducting focus groups. A professional focus group moderator was hired to conduct the Hispanic focus groups. The moderator for the African American group was recruited through a local graduate program and the American Indian moderator was recommended by the director of the American Indian health services center. Neither the African American or the American Indian woman had moderated groups before. These women were given a three-hour training on how to conduct a group and how to handle difficult situations, should they arise.

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Review of the focus group transcripts revealed the limitations of using inexperienced moderators. Although these women were able to create an atmosphere in which the focus group participants felt comfortable to speak candidly, there were instances in which probing of a response did not occur, limiting the depth of the discussion on key issues.

In addition to the moderator, another woman from the staff sat in on the groups, primarily to handle the audiotaping and to take observational notes.

Though videotaping was initially desired for all groups, the researchers decided against it. Reasons for this decision varied by group. African American women expressed the greatest level of distrust toward the research process and it was feared that videotaping would add to this distrust. Community agents within the American Indian community expressed concern about shyness and that videotaping would amplify discomfort. Similar concerns were expressed by the Hispanic community agents. It was deemed very likely that many of the Spanish-speaking women would be undocumented immigrants, who would be concerned about the threat of deportation if their status were identified by the government. Therefore, concerns of privacy were considered very seriously.

Summary

Researchers at AMC found the use of community organization techniques to be a very effective mechanism for recruitment of low income study participants. Although these techniques are more labor and time intensive than standard recruitment procedures, the effectiveness in recruiting eligible participants is greater.

It was clear that employing female moderators of the same racial and ethnic backgrounds as the participants was critical. Even in the recruitment process, it was very important that potential participants felt they could trust and feel comfortable with the recruiter. This was evident by statements made by some of the women when they were being recruited. However, use of inexperienced

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moderators was found to have some disadvantages. Although the inexperienced moderators who facilitated the African American and Native American groups did well in following the discussion guide and eliciting responses from the participants, they were not as effective in probing beyond the immediate responses of the women. Related issues that were put on the table by the participants were sometimes left without being further explored by the moderator, leaving potentially rich sources of information undisclosed.

In addition, the quality of the equipment used to record the focus group discussions and the skills of the transcriber are also extremely important in enhancing the ability of the report writer to draft a report that includes all important comments made by the participants. If the tape recorder is not effective in picking up participants' responses, or if the transcriber cannot discern a comment made by one woman from that of another, this will effect the quality of the written report.

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Suggestions for Conducting Focus Groups with Low Income Participants	
Recruitment	• Recruit in locations frequented by the populations of interest. • Use community organizing techniques. Identify gatekeepers in the community who can assist with the identification of eligible participants. Use a trusted member of the community to assist with recruitment by making the initial contact with potential participants. • Recruit on a face-to-face basis rather than by telephone. • Over recruit by approximately 50%. • Begin recruitment 4-6 weeks prior to scheduled groups.
Moderator Characteristics	• Use a moderator to whom the participants can relate and who is sensitive to issues important to the participants. • Use an experienced moderator, if possible. If using an untrained moderator, provide at least twelve hours of training which incorporates role play opportunities.
Conducting the Groups	• Conduct the focus groups in a community location in which the participants will feel comfortable. • Small groups with 4-6 participants are sometimes more effective than groups of 8-12 participants. • Provide incentives which are appropriate and relevant to your participants. • Provide transportation and childcare, if necessary.

◆ Appendix A: Screener's Questionnaire

Introduction:

"My name is _____, and I am working with a group of health care workers who are interested in learning more from women in this community about women's health concerns. We will be holding some group discussions (and some one-to-one discussions) with women over 50 years old over the next 2 weeks and were wondering if you might be interested in helping us out. The discussions will be about how we can help other women stay healthy. We will be paying the women who meet with us for their time."

If interested in participating, continue....

"I'll need to ask you a few questions since we want women with certain experiences to be part of the group."

Questions:

1. Are you 50 years of age or older? ☐ yes ☐ no (*ineligible*)

If yes, into which of the following groups does your age fall?

50 - 64☐

65 - 74☐

75+☐

If too young, skip to end, and thank the woman for her time.

2. Into which of the following groups does your annual household income fall?

< \$15,000.....☐

\$15,000-20,000.....☐

\$21,000-25,000.....☐ (*ineligible*)

>\$25,000.....☐ (*ineligible*)

3. How many people live in your household? _____

4. Have you ever had a mammogram? ☐ yes (*ineligible*) ☐ no

5. To which of the following racial or ethnic group(s) do you belong?

White/Anglo (non-Hispanic).....☐

Hispanic.....☐

Black/African-American (non-Hispanic).....☐

Native American.....☐

Asian.....☐

Or, some other.....☐

Refused.....☐

6. Do you, or does any member of your household work for a marketing research firm?
☐ yes (*ineligible*)
☐ no
7. Have you ever participated in a group discussion for the purpose of research, in which a group of people were brought together to discuss their experiences and opinions?
☐ yes
☐ no (*skip to invitation*)
- 6a. How long ago was that? _____
(*if less than 6 months ago, ineligible*)
- 6b. What topics were discussed? _____
(*if breast and/or cervical cancer, ineligible*)

If eligible:

Invite the respondent to participate in the group, providing the necessary information. Assure respondents that all information received will remain confidential. Obtain the following information from the respondent:

Name:	_____	Phone(h):	_____
Address:	_____	Phone(w):	_____

If ineligible:

Thank the participant for her time, telling her that unfortunately, we are unable to invite her to participate. Ask, however, if we can keep her name on file should a study come up for which we could use someone with her qualifications.

♦ Appendix B: Focus Group Discussion Guide

Introduction

Moderators introduce themselves.

A focus group is a small group discussion where about 10 people are brought together to explore attitudes about a particular topic of interest.

We don't know what you were told when you were called to participate in this group. But the topic we will be discussing tonight (today) is your attitudes about women's health care needs. In a focus group, there are no right or wrong answers, only opinions and we are really interesting in hearing from all of you.

I want to encourage you to listen and respond to each other as well as to me. Feel free to disagree with each other. If you disagree with something that someone says, tell us so and why. I want to hear many points of view.

You will notice from the microphone that we are tape recording our discussion so that it will help us remember what you said later when we write a summary. Is everyone comfortable with the use of a tape recorder? There is a one-way mirror. Behind it are some observers and they are there to take notes so they won't be in the way here.

Warm Up

I'd like to go around the table now and have each of you tell us your first name and a sentence about yourself. (quickly)

Background on Health

1. (General and quick - go around room) What are health problems that concern you most?
2. Where do you go for health care treatment or advice and who do you see there?

Listen for:

- neighborhood clinics
- hospital emergency room
- hospital ambulatory care
- physician in private practice

(Probe: Is this the SAME person you usually see?)

(Probe for each person: How do you get there?)

3. Many women are doing things these days to make sure they stay healthy.
 - a. What kinds of things do you normally do to take care of your health? (quickly)
(Listen for whether or not these people are "prevention-oriented" -- later note differences between adherers and non-adherers.)
 - diet
 - vitamins
 - exercise
 - physical exams
 - seatbelts
 - b. Are there any medical tests you get from your doctor or nurse to make sure you are healthy?
 - cholesterol testing
 - mammograms
 - Pap smears
 - c. Are there any other tests that some women get to protect their health?
 - d. In an examination, does a doctor or a nurse examine your breasts? (how often?)
4. Who do you turn to for help or advice with a health problem?
5. a. Where do you get information about health that you trust? Draw circle and arrows.
Probe:
 - doctors and nurses
 - magazines, which ones?
 - TV, which shows or commercials?
 - radio, which programs?
 - newspapers, which ones?
 - health fairs
 - friends
- b. Whose advice is most likely to make you change how you take care of yourself?
(put a * next to these credible sources)

Cancer

Some of you mentioned cancer as a health concern. (Or: No one mentioned cancer as a health concern -- is cancer something you worry about?)

6. What comes to mind when you hear the word "cancer"? (Probe for stories)
7.
 - a. What do you think happens to a person that gets cancer?
 - b. Do you think that most people who get cancer are going to die from it?
 - c. Is there anything people can do to improve their chances of surviving cancer?

Breast Cancer

8. Now I'd like to move on and talk for a while about breast cancer which is a health concern that some women think about.
 - a. Draw a stick figure: Here is a woman who will get breast cancer. Tell me about her. (age, race, life style, habits etc.)
 - b. Is there anything here that makes you feel more susceptible? Is breast cancer something that you personally need to worry about?
 - c. What do you think are the best ways to find out if a woman has breast cancer? (Probe: mammograms, breast self-examination, breast exam by a doctor.) How do all these ways compare? Are some better than others?
 - d. What do you think happens to a person with breast cancer? How could a woman improve her chances to be cured?

Knowledge and Perceptions of Mammograms

9. I'd like to talk for a moment about mammograms.
 - a. What do you think of when I say the word "mammogram?" How does that word make you feel?
 - b. For those of you who have heard of mammograms, where did you find out information about them?

10. Let's pretend that I'm from outer space, and I'm visiting earth for the first time and I've never heard of a mammogram. (Or just -- "Let's pretend that I've never heard of a mammogram.")
- What is a mammogram? Describe it to me.
 - Why would I want to get one?
 - Who needs to get a mammogram?
 - When should I have my first mammogram?
 - How often should I get one?

Perceived Benefits and Barriers to Mammograms

11. I'm wondering why you think that some women don't go for mammograms. Let's look at this picture of a nurse telling a woman about mammograms. This is a woman who may not want to have a mammogram. (cartoon of nurse talking to woman -- woman has a cartoon cloud of what she is saying and another of what she is thinking.)
- What is the nurse saying to this woman about mammograms?
 - What is the woman saying to her?
 - What is she really thinking? (Probe for reasons that she really doesn't want to get a mammogram.)

List on chart: Barriers to mammography

Probe:

- cost
- fear (Probe: fear of what? Let's explore this a little more ...)
- fear of discomfort
- fear of finding cancer (Probe: Does finding cancer early help?)
- fear of radiation
- fear of the costs involved in care for cancer
- never thinks about it
- no time or energy
- doesn't want to take time off from work
- child care problems
- no transportation
- too far
- doesn't want to look for trouble

12. a. Now let's talk for a minute about your personal experiences. How many of you have never had a mammogram? Has anyone ever suggested that you have one? (Probe)

b. Why have you not gone for a mammogram? (Continue listing barriers)
13. (Read the list of barriers on the chart) Question to all the women:
 - a. Are there other reasons why some women might not have a mammogram? (Of those of you who have had mammograms, are there some reasons why you almost decided not to have a mammogram?)
 - b. Which of these reasons are the most important -- would absolutely keep some women like you from getting a mammogram? (put * next to mentioned barriers) (spend time probing on this question)

Cost as a Barrier

14. You've told me reasons why some women may not go for mammograms. Let's talk a little more about a couple of these reasons. Let's first talk about "cost".
 - a. To what degree would cost stop you from having a mammogram?
 - b. Mammograms vary in cost from place to place. How much do you think a mammogram costs (take guesses)?
 - c. Does your insurance cover mammograms?
 - d. How much are you willing to pay every year to have a mammogram?
 - e. How about if it were free, do you think that more women would have them? (why or why not?)

Location of Facility as a Barrier

15. Some of you mentioned that getting to the place where mammograms are given is difficult.
 - a. Ideally, where would you want to go to have a mammogram?
 - b. Where would you not want to go?

- c. How would you feel about getting a mammogram at a mobile mammography van if it were offered in your neighborhood?

Probe:

- Any feeling of going to a mobile unit
- Concern over how good the equipment is?
- Concern over radiation?
- Concern over who will read the mammogram?
- "Ambiance" of the mobile unit
- When should it be offered? (days, hours)
- Where should it be offered? (work, home, shopping center)
- What is the best way to let women know when and where it will be offered?

16. Now I'd like to ask the rest of you who have had a mammogram:

- a. Why did you go for a mammogram: (List on chart reasons to have mammograms)

After list is complete look at items and ask those who have not had mammograms about them. For example: "My doctor recommended that I get one so I did." Ask the "never-hads": "Did your doctors or nurses ever recommend that you get one?" or, for "I saw an ad on TV," ask, "Did you ever see that ad?"

- b. How many mammograms have you had?

- c. Tell me a little about your experience.

- How did you get the results?
- Did you understand the results?

- d. Was there anything about the experience that influenced you not to go back for another mammogram?

Mammography: Unanswered Questions

17. What do you want to know about mammograms that you don't know now? (List)

18. We touched earlier on the breast exam. Has a doctor or nurse examined your breasts? When and where did you have it done, and when will you have it done again?

Strategies of Promotion of Mammography

19. Let's say that we want to launch a campaign through a neighborhood center in Sterling (Downtown Denver). Let's say that we have been given government funds so that women in this community can get mammograms free or at low cost. You have been chosen as the committee chairperson to develop a plan to encourage all women over 40 in the community to have the mammograms. You have been given unlimited funds to

implement this program. You are in charge of deciding what it would take to convince women like yourselves to have the mammograms. Let's brainstorm.

Listen first -- then probe:

- a. What would be the most effective way to let women know about this program?
 - brochures
 - TV (which celebrities?)
 - community organizations (which ones? churches? community centers?)
 - what clubs, groups, or organizations do you belong to?
 - how would you work through such established organizations?
 - b. What message (a few simple points) would you tell women in order to convince them it is important to have a mammogram?
 - c. **How would you communicate "Mammogram" to these women who may be unfamiliar with the term? How would you describe it simply in a way that they can understand?
 - d. How could we make actually getting the mammograms as simple as possible for the women?
 - Where should they be offered?
 - What hours?
20. **Let's look at the list we made earlier of reasons why you think that some women don't go for mammograms. (Look at each reason and ask "In our campaign, what can we do to overcome")

Cervical Cancer

When we discussed health concerns, some of you mentioned cancer. Another kind of cancer that affects women is cervical cancer. Let's talk for a moment about cervical cancer.

21. a. What is the best way to detect (find out if you have) cervical cancer?
- b. Who do you think needs to get a Pap smear? (Probe on age?)
 - c. What are some reasons to have Pap smears? (list)
 - d. How often do you think women need Pap smears?
 - e. How many of you have had a Pap smear in the last three years?
 - f. What do you think are some reasons some women don't get Pap smears?

Probe:

- don't think that they are at risk
- doctor never told them they needed one
- inconvenience
- no time
- too far away
- no child care
- cost
- it is embarrassing
- lengthy waits to get one

22. Of these reasons, which do you think are the most important ones that would keep women from having a Pap smear? (put a * next to these reasons on chart)
23. If we were going to think about a campaign similar to our mammography campaign for Pap smears what would it be like? What would this message be?
24. Before we close, is there anything else you want to add to our discussion?

Thank you for participating!

◆ **Appendix C: Sources of Focus Group Reports Used in Comparison**

AMC Cancer Research Center

American Cancer Society

Arkansas Cancer Research Center

College of Physicians and Surgeons of Columbia University

Connecticut Department of Health Services

Fox Chase Cancer Center

Illinois Department of Health

Maine Bureau of Health

Medical College of Virginia

Memorial Sloan-Kettering Cancer Center

Minnesota Department of Health

National Cancer Institute

New Mexico Department of Health

North Dakota Department of Health

Rhode Island Department of Health

San Diego University and University of California at San Diego

Sangamon State University

University of South Carolina

University of Maryland

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